



IPOPI 3RD REGIONAL ASIAN **PID MEETING**

ONLINE

SEPTEMBER 18-19
2020

MEETING **REPORT**

INTRODUCTION

IPOPI had the great pleasure of welcoming delegates from 19 countries from the Asia-Pacific region to the virtual **3rd Regional Asian PID Meeting**, held on 18-19 September 2020. During this well attended online meeting, the participants learned from both international and regional primary immunodeficiency (PID) experts on the latest developments, for PID in Asia. The meeting was organised over two days with **the first day focused towards doctors and the second towards patient organisations in the region**. Both days were well attended by both doctors and patient representatives.

The meeting was initially scheduled to take place in Kyoto, Japan, in September 2020, back to back with the **JSA/WAO/APAPARI 2020** Congress. After careful consideration of the ongoing spread of COVID-19 worldwide and in order to ensure the safety of all participants, IPOPI decided to move this meeting online with a shortened programme. We seized the opportunity to organise a great meeting featuring the latest in PID treatment and care, packaged in a new online format.

Our in-person doctor and patients' meetings are a very important part of our activities and moving the meeting online was a way to ensure that we could all still come together, interact and discuss the priorities of the PID community. The new format also allowed for participation from countries new to the PID community. IPOPI could not be more pleased with the outcomes of the meeting.

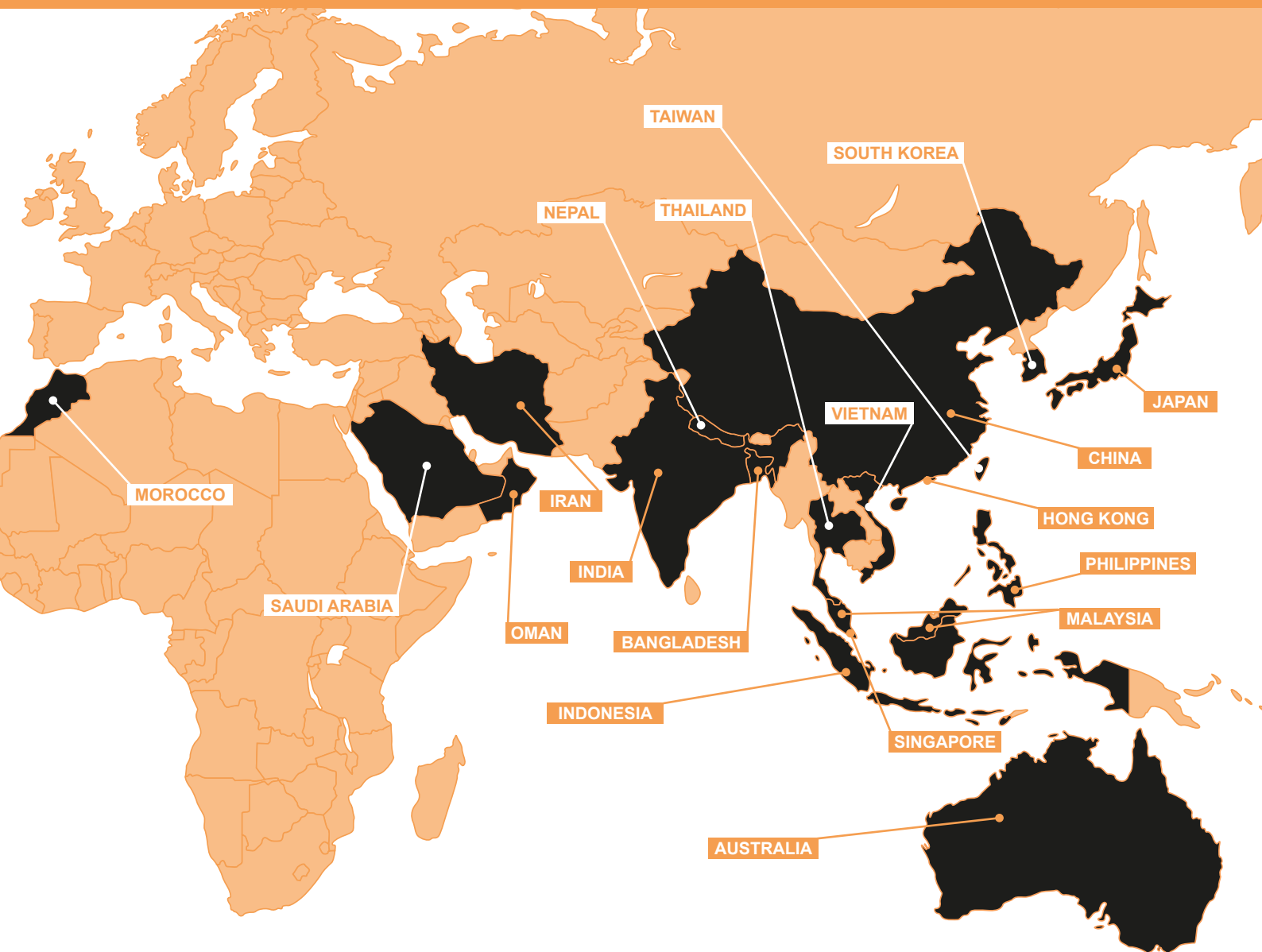
PARTICIPATION OVERVIEW

TOTAL REGISTRATIONS: 177

TOTAL PARTICIPANTS: 126

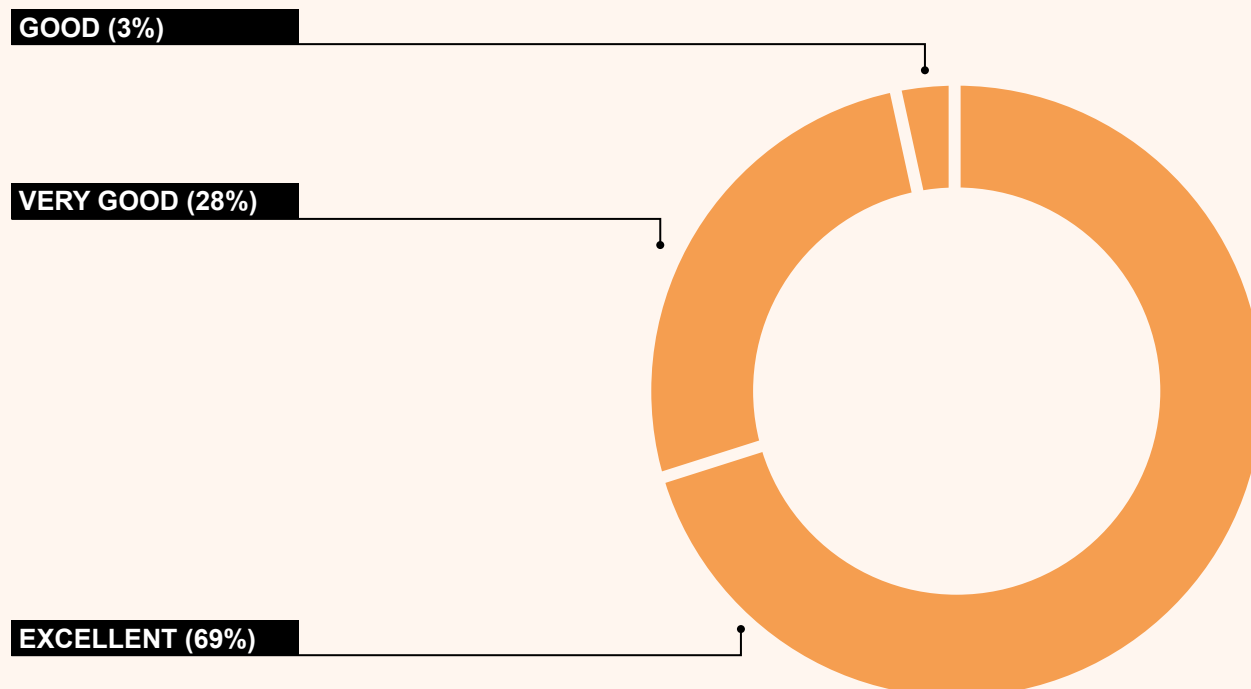
COUNTRIES REPRESENTED: 19 (Australia, Bangladesh, China, Hong Kong, India, Indonesia, Iran, Japan, Malaysia, Morocco, Nepal, Oman, Philippines, Saudi Arabia, Singapore, South Korea, Taiwan, Thailand, Vietnam).

To accommodate the wide range of participants, **the meeting offered on-demand language interpretation in 9 languages spoken in the region** (Japanese, Bengali, Chinese (traditional and simplified), Hindi, Korean, Tamil, Vietnamese, Arabic). This was an appreciated tool that enabled participation from delegates who might not have been able to take part in the meeting otherwise.



PARTICIPATION FEEDBACK

OVERALL EXPERIENCE RATING (n=29)

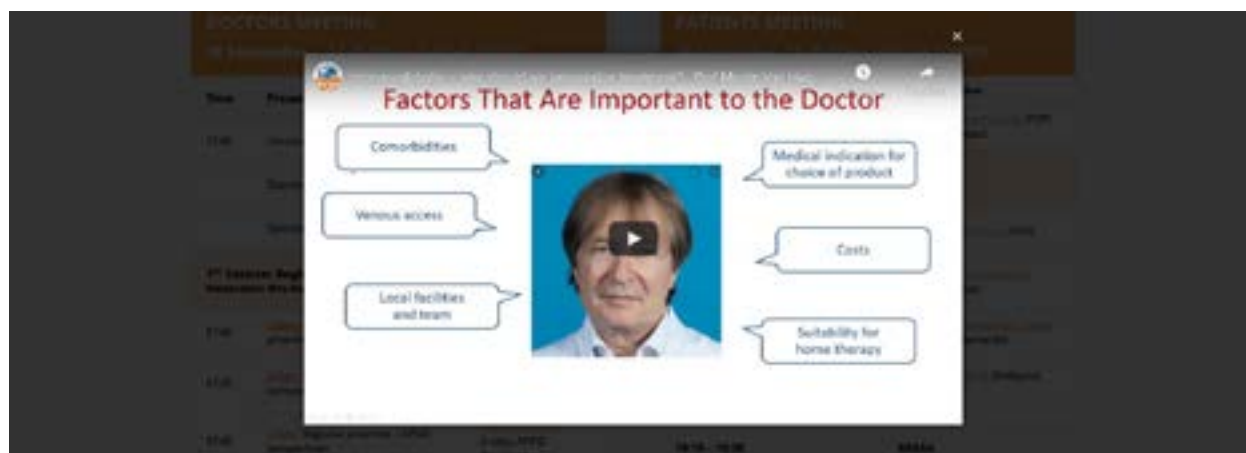


"This is my first-time participation in the IPOPI meeting. It was very fruitful and informative time. Thank you very much for organizing!"

"I joined for the first time. It was very valuable experience. Thank you so much."

PRESENTATIONS AVAILABLE FOR REPLAY

This meeting offers the opportunity to replay the presentations for educational purposes. The service is available for all presentations which have been approved by the respective speakers.



DAY 1 – CLINICAL CARE MEETING

18 SEPTEMBER

SESSION 1: REGIONAL CLINICAL PRIORITIES (MODERATED BY MRS MARTINE PERGENT)

- Introduction and welcome, **Mrs Martine Pergent**, IPOPI President
- Sponsor's welcome, **Mr Kenji Misawa**, Takeda
- Sponsor's welcome, **Dr Christine Jendrsczok**, Kedrion
- PID diagnosis and care priorities in Japan, **Prof Koshuke Imai** (Japan)
- Regional priorities – SEAPID perspectives, **Dr Narissara Suratannon** (Thailand)
- Regional priorities – APSID perspectives, **Prof Surjit Singh** (India)
- Questions & Answers, **Mrs Martine Pergent & Dr Nizar Mahlaoui** (France)



Mrs Martine Pergent



Professor Koshuke Imai



Dr Narissara Suratannon



Professor Surjit Singh

The meeting was opened with an introduction and warm welcoming words from IPOPI President **Mrs Martine Pergent**. She expressed gratefulness to be hosting this meeting for the third time, and gratitude to all physicians and patients from the region who have supported the preparation of this meeting and contributed to its success. Following a brief sponsor's welcome, the participants enjoyed a fruitful session on Regional Clinical Priorities.

The three speakers, **Professor Koshuke Imai**, **Dr Narissara Suratannon** and **Professor Surjit Singh**, touched upon different aspects of the diversity in this region. Prof Imai introduced the participants to the current situation in Japan for PID patients. He was followed by Dr Suratannon who showed the great work done by the South East Asian PID Network (SEAPID) and discussed regional genetic diagnostic issues and SCID newborn screening. Prof Singh contributed with the APSID perspective and emphasized the diversity of the region, with some countries being quite advanced in terms of PID care and others having a longer journey ahead. The three speakers contributed with three excellent presentations and provided a comprehensive snapshot of the region.

SESSION 2: PID MANAGEMENT (MODERATED BY MRS CHRISTINE JEFFERY, IPOPI VICE-CHAIR)

- Management of severe PIDs during childhood: where do we stand in Asia? **Dr Pamela Lee**, (Hong Kong)
- Managing PIDs in adult patients with crossover conditions (autoimmunity, autoinflammation), **Prof Martin van Hagen** (Netherlands, Thailand)
- Transition care: managing the adult patient of tomorrow – the next challenge for Asia? **Dr Nizar Mahlaoui** (France)
- Questions & Answers, **Mrs Christine Jeffery** (IPOPI Vice-Chair) & **Dr Nizar Mahlaoui** (France)



Mrs Christine Jeffery



Dr Pamela Lee



Prof Martin van Hagen



Dr Nizar Mahlaoui

The second session explored PID Management from three different angles, guided by IPOPI Vice-Chair **Mrs Christine Jeffery**. To begin, the participants enjoyed the great opportunity to learn from **Dr Pamela Lee** about Management of severe PIDs during childhood in Asia. Dr Lee showcased an inspiring example of how regional cooperation led to the first unconditional haploidentical stem cell transplantation in a young patient with severe combined immunodeficiency (SCID) in Vietnam. The two following presentations by **Professor Martin van Hagen** and **Dr Nizar Mahlaoui** explored management from two angles. Prof van Hagen provided an overview of how to Manage PIDs in adult patients with crossover conditions and Dr Mahlaoui explored transition care and the challenge this may pose for Asia. These were two appreciated topics, visible in the busy Q&A session that followed.

HKU Med
Department of Paediatrics & Adolescent Medicine
香港大學兒科及青少年科學系

Ig replacement for PID in Asia: Dynamics in demand and supply

| Demand | Supply |
|--|--|
| - More PID patients being diagnosed, along with patients with other diseases which Ig therapy is indicated | - Domestic product vs imported product |
| - Longer life expectancy | - Sufficiency of domestic plasma collection to sustain loco-regional use |
| - Geographical accessibility: more centers with physicians trained in PID providing PID service | - Efficiency of plasma fractionation |
| - Financial accessibility: policy change in reimbursement | - A diversification of plasma supply / Ig products appears desirable for political, socio-economic and health policy reasons |
| - Physician education: indications, dose optimization | - Resilience at times of demand surge from other emerging indications and reduced supply of imported products |

Challenge: how to ensure adequate provision is made for PID patients in the context of competing demands for Ig

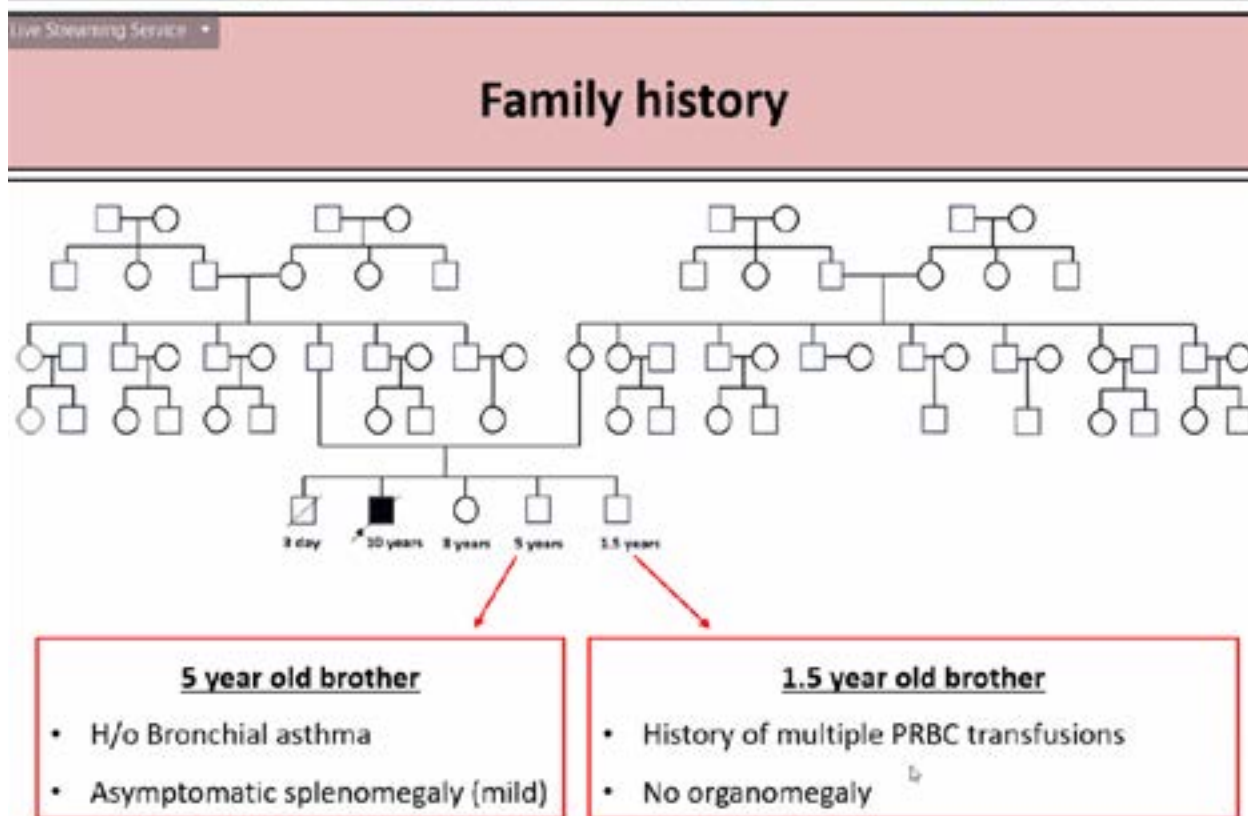
Dr Pamela Lee (Hongkong) presenting



COMPLEX REGIONAL CLINICAL CARE CASES (MODERATED BY DR NIZAR MAHLAOUI)

- 1st case presentation: Rare presentation of ADA 2 deficiency as hypogammaglobulinemia with Hodgkin lymphoma, **Dr Murugan Sudhakar** (India)
- 2nd case presentation: Multiple infections, skin lesions and hepatosplenomegaly in a newborn baby, **Dr Masahiro Ueki** (Japan)
- Panel of Experts: **Prof Le Thi Minh Huong** (Vietnam), **Prof Martin van Hagen** (Netherlands, Thailand), **Prof Surjit Singh** (India)

To end the first day the participants were invited to learn from a dynamic panel discussion of Complex Regional Clinical Care Cases, led by **Dr Nizar Mahlaoui**. The panelists **Prof Le Huong**, **Prof van Hagen** and **Prof Singh** all contributed their expert knowledge to discuss the complex case study presentations provided by **Dr Sudhakar** and **Dr Ueki**. Both case presenters were not only provided with food for thought by the experts, but by the audience as well. This was an appreciated session with a very interesting exchange of experiences from both junior and senior doctors.



Dr Murugan Sudhakar (India) presenting.

DAY 2 – PID PATIENTS MEETING

19 SEPTEMBER

SESSION 1: EDUCATIONAL LECTURES (MODERATED BY MRS MARTINE PERGENT)

- Welcoming words, **Mrs Martine Pergent**, IPOPI President
- IPOPI – the journey so far in Asia, **Mr Johan Prevot**, IPOPI Executive Director
- Over 400 PIDs for children and adults – what does it mean and how do we deal with it, **Dr Nizar Mahlaoui** (France)
- Immunoglobulin – why should we personalize treatment? **Prof Martin van Hagen** (Netherlands, Thailand)
- From BMT to gene therapy: overview of recent developments, **Dr Adli Ali** (Malaysia)
- Question & Answers, **Mrs Martine Pergent** (France)



Mrs Martine Pergent



Mr Johan Prevot



Prof Martin van Hagen



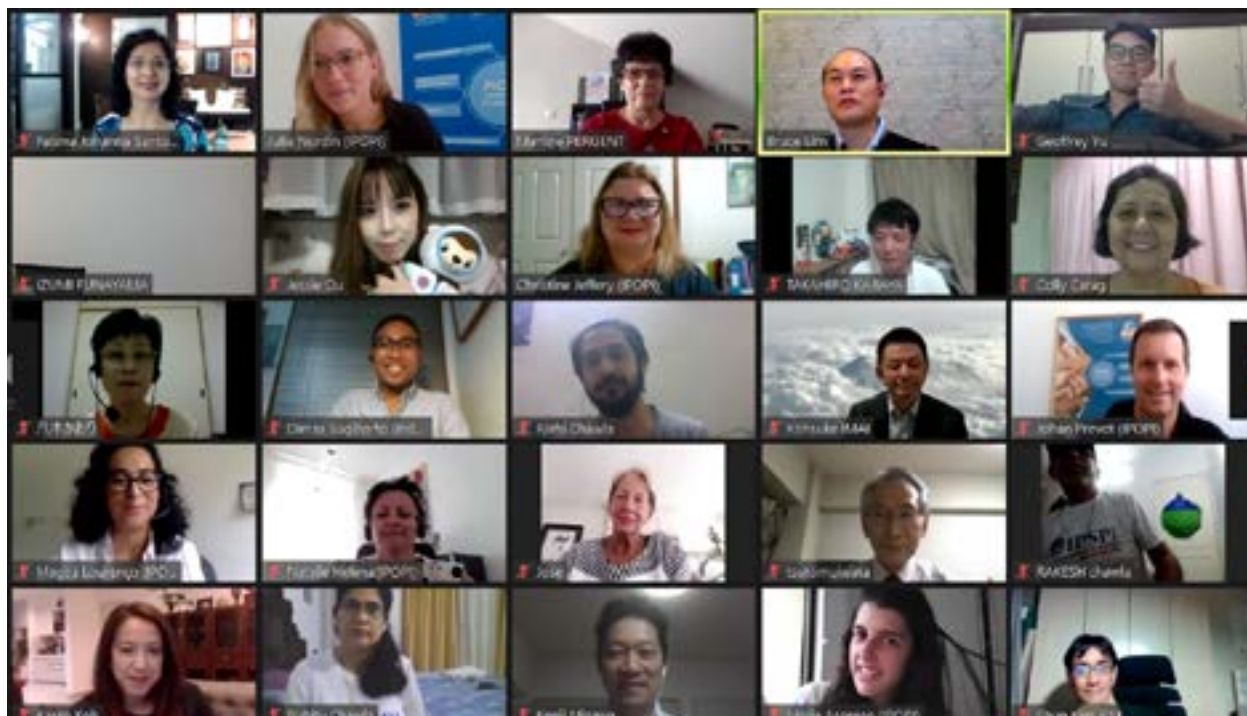
Dr Nizar Mahlaoui



Dr Adli Ali

After focusing on Clinical Care during the first meeting day, the second day came in the shape of a PID patients meeting for IPOPI's national member organisations in the region. **Mrs Martine Pergent** opened the day and invited the participants on an *“educational trip through the great region to learn more about primary immunodeficiencies.”* She also emphasized that patient leaders should join forces to raise awareness on these conditions and improve access to diagnosis and treatment, something vital for the quality of life for PID patients in Asia. Following this introduction **Mr Johan Prevot**, IPOPI Executive Director, provided an overview of IPOPI's long and successful history working with doctors and patients in Asia. He highlighted that IPOPI will continue to strengthen this cooperation in the many years to come.

The second part of this session featured an introduction to 400 PIDs by **Dr Nizar Mahlaoui** and an exploration of personalized immunoglobulin treatment by **Professor Martin van Hagen**. Not only did Professor van Hagen give the audience an overview of the importance of personalizing immunoglobulin treatment, he also widened the understanding of the alternatives available for patients. The final presentation was given by **Dr Adli Ali**, who showcased the latest developments of BMT and gene therapy and compared the two. These presentations inspired to a lively Question & Answer session where the speakers continued to share their appreciated knowledge.



SESSION 2 – WHAT’S UP IN ASIA? (MODERATED BY MR BRUCE LIM, IPOPI TREASURER)

- NMO updates on recent achievements: sharing best practice, NMO representatives
- What is a SWOT and how can it help fine tune your strategic plans? **Julia Nordin**, IPOPI NMO Programmes Officer
- NMO Country SWOTs & Identification of national priorities
- Identification of common regional strategic priorities and next steps, **Mrs Christine Jeffery**, IPOPI Vice Chair
- Closing remarks, **Mr Bruce Lim**, IPOPI Treasurer



After a fruitful educational session, it was time for the participants to engage in an interactive workshop led by Mr **Bruce Lim**, IPOPI Treasurer. To kick start this session 9 NMO representatives were invited on the virtual stage to present a recent achievement from their respective patient organisations, providing a great insight in their work. This was followed by an interactive **SWOT workshop** presented by **Ms Julia Nordin**, IPOPI NMO Programmes Officer. The objective of this workshop was to provide the participants with the right mind and skill set to engage in strategical planning and convey the message that strategic planning is not complicated. During the workshop, each group was asked to identify **Strengths**, **Weaknesses**, **Opportunities** and **Threats** for the PID Community in Asia. The participants were divided into different groups based on language, allowing participants to speak their national language in many groups. Based on the SWOTs and the common issues, strategic regional focus areas were identified and discussed by **Mrs Christine Jeffery**. Moving forward, these will serve as a basis to lead additional discussions and strategic planning sessions with IPOPI's NMOs in the region.

REGIONAL STRATEGIC FOCUS AREAS

DIAGNOSIS

Key action: Improve diagnosis through advocacy and awareness

TREATMENT

Key action: Improve access to treatment by communicating with government and Ministries of Health

MANAGEMENT

Key action: Improve PID Management through collaboration with physicians

AWARENESS

Key action: Raise awareness through education and events

COLLABORATION

Key action: Strengthen multi-stakeholder collaboration to expand PID programs and events

CAPACITY

Key action: Build capacity to improve quality of life people living with PID

SUPPORT PATIENTS

Key action: Support PID patients and families through education and advocacy

CONCLUSION

The 3rd Regional Asian PID Meeting was a successful virtual event, focusing on the importance of regional cooperation for all PID stakeholders in Asia. It was a well-visited and appreciated meeting with participants from the entire region, strengthening the sense of community. Despite the fact that the meeting could not take place in Kyoto as planned IPOPI was delighted to see a strong Japanese attendance. It was also a pleasure to welcome participants from countries such as Nepal and Bangladesh, who have not previously been represented in IPOPI meetings. IPOPI has a long history of collaborating with patients and doctors in Asia and we look forward to continuing this journey in the years to come.

This meeting was supported by unrestricted grants from



